

Embodied Activism: Constructing a Transgressive Self

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Narratives grounded in everyday experience and practice reveal a different kind of activism in an academic setting. Narratives literally 'take place', that is, they mark the territory that is to be the ground for meaningful action (Grumet, 1987). In the context of the academy, I construct a transgressive self (Lenzo, 1995) as a woman with a disability. Using autobiographical narrative focused in a critically self-reflexive way on my experience of being a disabled graduate student, I explore, deconstruct, and reconstruct taken-for-granted thinking about what it means to be a woman living with an episodically visible disability. As an activist studying in traditional settings challenging traditional disciplinary canons, I also challenge dominant understandings of women with disabilities.

By constructing myself transgressively, I reinvent myself in ways that also problematize understandings of what activism is, how it happens and in what locations. And so I open myself to counter-hegemonic cultural practice as a woman and as a woman living with chronic illness by naming "that location from which I come to voice - that [embodied] space of my own theorizing" (hooks, 1990, p. 146), autobiographical writing.

This paper is very much a work-in-progress (or a working out in progress), that is, it works at mapping out some of my experiences and my current thinking about them. My aim is to begin to connect, however loosely or tentatively, my experiences with different ways of thinking about disability, what it is like to live in a chronically ill body, and activism. Readers will notice - at the risk of being labelled a member of the "true confessions brigade" (Oliver, Barnes & Barton, 2000, p. 6) - I am explicitly working from the inside/out. As a feminist, using my own experiences as the ground for my thinking, analysis and activist practice is a deeply subversive and political move.

I am concerned about any move to devalue this and privilege the outside/in as Oliver, Barnes and Barton (2000) suggest. Privileging the outside over the inside is a dichotomizing and hierarchical move with troubling effects in the lives of women with disabilities and others located at the margins of the disability movement. What is more important in our scholarly and activist practices is that we are clear about the nature of the interactions between inside and outside, including their tensions, contradictions and effects, regardless of the order in which they appear. This order must always be contextual, not applied rigidly or a priori to any given situation, experience or practice.

Moira Gatens (1992) reminds us that "writing is a political issue and a political practice...for feminists" (p. 133). By examining how language around denial/acceptance constructs the everyday reality of living with chronic illness I reveal how language has the power to make invisible the particularities of my day-to-day experiences as a woman living with disability. Intersections with others who have the power to define/erase/take up my experience are considered as I then reflect on the experience of "passing" and how it implicates myself and others.

Staying with embodied reality allows me to position myself variously, to see how, as Chouinard (cited in Dyck, 1996) suggests, power is exercised through "multiple sites of experience and practice, in virtually every aspect of [my life]." It also allows me to experience how "challenging our oppressions requires reinventing ourselves...and our relations to others" (Dyck, 1996, p. 58). I have read several different versions of "Constructing a transgressive self" (below) to seminars of doctoral students garnering mixed responses. I consider writing and reading this autobiographical text a part of my embodied activism in the acade-

my and a primary way I construct myself transgressively, and do so here to open this activism to a wider audience.

Constructing a Transgressive Self

I am a woman living with chronic illness of fluctuating 'visibility' engaged in doctoral studies at a university that has no department of disability studies or even disability studies curricula of any kind. From time to time, one discipline or another will offer a course focused on different aspects of disability, for example, social work practice with people with disabilities. Rarely is any effort made to consult with people living with disabilities about course content and process and even more rarely are these courses taught by people with disabilities. To further complicate matters, I am an interdisciplinary student studying in two disciplines, education and nursing, in which I have previously obtained degrees. These are my official locations in the academy.

Unofficially, I also locate myself in women's/disability studies and feminist political science. Disability studies scholars will recognize the 'applied' fields of nursing and education as two whose "domains of knowledge [are] divided up and clustered so as to render a partial or distorted picture of disability [leading to] particular social practices" (Linton, 1998, p. 76). In each of these disciplines, the curriculum focuses on practice - as a teacher or clinician - constructing people with disabilities primarily as students, clients or patients.

As a woman living with disability, I am also one of those patients whose lives are controlled by professionals who practice in paramedical disciplines. Most people living with chronic conditions and/or disability will recognize this statement: "You must learn to accept your disability."

Even though I do not remember any one health care professional saying this to me, I have internalized it as a credo subscribed to by health care professionals and others whose practice is, ironically, to some degree dependent on my non-acceptance. This belief is implicit in everything they do. If I appear to refuse to do this, their 'interventions' are 'unsuccessful,' likely because I am being 'non-compliant.'

Couched in the language of empowerment, further 'interventions' are geared towards moving me closer to the acceptance end of a hypothetical acceptance/denial continuum which overlaps closely with a hypothetical compliance/non-compliance continuum. Interestingly, from the perspective of health care practitioners, compliance remains somewhat of a conundrum. Donovan and Blake (1992) report that by 1985 at least 4000 English language articles focused on non-compliance had been published with an additional 4000 listed on Medline by 1990. Most of this research attempts to explain and control non-compliance (Thorne, 1990).

Since the onset of my chronic condition, I have come to understand denial and acceptance (and compliance) as ways medical/psychological discourse constructs my experience of living with disability. What this discourse makes invisible is the relationship I have with unpredictable bodily experiences and how I choose to be present with and respond to these, including the experience of difficult embodied processes (such as chronic pain and profound fatigue). Responding to fluctuating states itself is as uncertain and unpredictable as the chronic condition with which I live and is determined by a complex web of factors at play in each particular situation (not just a cost-benefit analysis as suggested by researchers studying compliance).

I reject the idea that health care professionals know what is best for me (to which I must comply). If I were to configure these experiences in some way, I would say they create a spiral or a helix of some kind in which I can find myself at different places on that spiral, given differing circumstances. I question whether there is some magical end point at which I "totally accept" the illness or disability with which I live. Rather, there are many negotiations with self I make every day, central to living with chronic illness, which constitute the experi-

ence of 'acceptance'/'denial'.

Daily and sometimes moment-to-moment negotiations with self undermine the idea of a fixed state of denial or acceptance. Should I attend my weekly meeting with the women doctoral students I have befriended despite the fact that I am especially stiff and sore and tired today? It is important for me to be involved in things, to have a productive life, so it is hard to say no and occasionally I will get a burst of energy from being with others or working on something I consider worthwhile or important (like this article). If I go despite my symptoms, am I denying my illness? Or not accepting it? Neither, really. I am responding in a certain way to a complex set of circumstances and taking responsibility for being present or absent affects me personally. To label it denial or acceptance overlays it with a value judgement about what I am supposed to be doing set against some externally imposed standard - developed and subscribed to by non-disabled professionals - of how a person is supposed to live with a chronic condition, in this case rheumatoid arthritis.

Questions about the in/visibility of my disability arise from these considerations. If I am visibly missing from my group meeting or a seminar that I would usually attend is my disability visible or invisible? Or both? If I am physically present in a meeting or classroom, how do I decide whether or not to include my disabled subjectivity/self, to make visible my life, to avoid erasure? It depends.

Telling the truth about my body and my life might force me to transgress the boundaries of conventional discourse, to utter what is unspeakable (Mairs, 1996) about my experience. The decision to bring to voice my embodied subjectivity depends on my reading of others' receptivity to hearing about, for example, the material constraints I live with, my engagement with other disabled women in social action towards justice, and how these construct my life as a woman and a graduate student struggling to advance her career. It also depends on how it has/not been responded to in the past. My own sense of whether I have the energy, spirit and support (from allies) for speaking, which partially depend on levels of pain, stiffness and fatigue, are also part of this negotiation with self.

Rarely, especially in classroom settings, does the embodied (and political) reality of living with disability become central to collective critical/pedagogical concerns, despite the presence of valuable knowledge embedded in this particular experience. Many of my peers are practitioners who by and large enter their doctoral studies with traditional views of practice with women with disabilities. Although I have non-disabled allies, as a disabled student in the academic setting, I work alone (and constantly) at creating space for disability discourse. I engage in this activist practice by critiquing taken-for-granted understandings when they surface in discussions and by sharing autobiographical writing about what it is like for me to live with chronic illness.

I am not always successful at establishing ground and have left seminars wondering if people just view disability as something that primarily concerns me, and perhaps, tangentially, them. The knowledge I have then becomes erased, invisible and inaccessible to the disciplines in which I study, disciplines that could be enriched by learning how a person whose body began to fail her in early adulthood actually lives in the world. After all, most people will experience this sooner or later. Perhaps my actions (including absenting myself or remaining silent) point to "the astonishing continuity of [disabled] women's imagination of survival, persisting through the great and little deaths of daily life" (Rich, 1986, p. 148). I see that where I am situated is a space in which I can remain open, where I can resist closure on my own (and others') experience of disability, a space of radical openness, a site of resistance (hooks 1990).

I live in a world which has difficulty with a person who is "ill," or worse is "ill" but appears "well." Inside I feel pressure to portray myself as either "sick" - and appropriately fill my role as a person with a chronic condition - or "not sick." In our society, chronic illness seems to mean chronic misery and unhappiness. With the first painful symptoms of the

disease I had entered an unfamiliar world in which, as Sue Wendell (1996) suggests, illness became a constant reminder to myself (and others) of the inability of science and medicine to protect us from disease, disability, and death. In a society that idealizes bodily perfection, I became the imperfect "Other" who could never come close to the ideal. In addition, "curiosity about medical diagnoses, physical appearance, and the sexual and other intimate aspects of disability is common: interest in the subjective experience is rare" (Wendell, 1996, p. 91).

However, I have developed special knowledge living in this formerly alien world, like how to live with a painful body and fluctuating physical states, uncertainty, and indeterminacy. I have also learned how to live with a chronic incurable degenerative condition that daily reminds me of my 'failure' to rise above what is prevalent in dominant (Western) discourse, the separation between the (devalued, female) body and (superior, male) mind. As a woman socialized in/by white Western society I had learned I could transcend my body just by exerting the right amount of energy and attention (Wendell, 1996). By reconnecting my thinking and speaking with my body as part of my doctoral work, I demonstrate efforts not to transcend my body, but to reclaim it (Rich, 1986).

As a disabled woman, I am challenged to accept myself and my limitations in the context of a society that not only devalues less than perfect physical (and mental) health, but defines 'health' narrowly as the absence of illness. This does not allow for experiences of being healthy while living with chronic illness. Being a doctoral student has fostered my 'health' which I believe largely depends upon having access to opportunities, resources and supports I need to participate in society as fully as possible. Further complicating the experience of health is my (fluctuating) ability to 'pass,' that is, many people when they first meet me do not notice the deformity in my hands and feet, unless I am wearing a wrist splint or walking with a cane. And the pain and fatigue I live with leaves me in the grey zone of ambiguity.

What am I doing when I am "passing"? I am minimizing differences between myself and others so that I am not treated as "Other." I am trying to assimilate. How do I do this? I do not wear my wrist splints unless I absolutely need them. I wear 'normal' shoes, not specially-designed orthopaedic ones. I walk with an even gait as much as possible. I attempt to hide the pain I am feeling. I refrain from asking for help unless I am too stiff or weak to lift things, open doors, jars, fasten buttons. I stay at home (and often in bed) when I am profoundly fatigued, or have a lot of pain. I carry papers and books in a shoulder pack, rather than a briefcase. I look people directly in the eye when I speak/listen to them. Am I in denial, not letting my 'freak flag fly'? Perhaps. Yet, I am also a person who meditates an hour each morning and once weekly in a woman's sangha, engaging in a practice that modifies my experience of pain, improves my body functioning and achieves some harmony between body and mind (Meekosha, 1998). Is this denial? Acceptance? Compliance?

Passing comes at a cost. In passing, I abandon my history and my body and take on another appearance because my own is insufficient. Thus, I cheat myself of "the chance to define [myself] and to make mutually respectful and strengthening alliances with other self-defining people" based in the fear of "naming [myself] lest name be twisted into label" (Rich, 1986, p. 142). Like being called 'an arthritic', an act of objectification which threatens my sense of agency (Todoroff & Lewis, 1992).

Passing also brings up doubt about my own level of illness and disability. It is framed in a question that lives inside me, but punctures the surface on days when I am relatively pain and stiffness-free and mobile with enough energy to complete planned tasks, the disability hidden, submerged. The question is simple enough, "What if I'm not really disabled?", but it feels like the door to a roomful of complicated, troublesome considerations about who gets to define disability, who fits the definition (or not) and why/not. To the institutions that send me disability pension benefits monthly, which I need to support my studies, appearing non-disabled (passing) could be construed as being "not disabled" - for insurance

purposes - and for me a potentially precarious financial path.

So rather than pass, when the yearly forms arrive in the mailbox requesting me to verify my disability, I minimize my abilities, or indicators of health. I portray myself as being at the very 'disabled' edge of this fluctuating illness. It is not that this is a lie, it is just that it is a partial truth, one that has the effect in my life of potentially undermining my hard-won sense of self as capable and competent. I do not really know how it gets decided that I can continue receiving benefits or who actually makes the decision. It is no one I have ever met. Perhaps that is a good thing because I would hate to reveal my abilities for fear of jeopardizing my income. I would hate to pass.

What else might this autobiographical writing be about? Situated as the (speaking/writing) subject, I am attempting to shift my own and others' understandings of what it is like to be a woman living with a disability beyond dichotomous oppositions (disabled/abled-bodied) that "invariably [absorb] alterity into the hegemonic and familiar" (Gunew & Yeatman, 1993, p. xiii). I am trying to displace the "tyranny of the familiar" (p. xiii). I am doing this by telling the reader how I negotiate the complex reality of living with a disabling chronic condition and the effects of doing so in my everyday lifeworld as an Interdisciplinary doctoral student. In doing so, I construct a situated, decentred, multipositioned self - a transgressive self (Lenzo, 1995) which challenges the abled/disabled dichotomy and its usefulness for my life as a graduate student living with a chronic condition.

Through the autobiographical texts I create, I make the statement that the activism I engage in is not something that is necessarily limited exclusively to the public sphere. I do this in several locations - at the level of my own subjectivity and in the context of a public site, such as in Faculty of Education seminars with non-disabled colleagues - both deeply political. Viewing my own subjectivity as a process opens me to the possibility that I am capable of change and therefore capable both of acting to change social practices and of transforming myself, as one small part of constituting a new kind of society (Belsey, 1985). This activism is embodied partially because my writing/speaking focuses on living in my body in ways that challenge dominant representations of disability.

How do I understand the embodied space hooks (1990) refers to? What might embodiment be? And how do I understand its location in disability discourse? Moss and Dyck (2000) refer to embodiment as a lived space - the juncture point of discursive and material bodies - that also entails connecting to other (material and discursive) bodies in concrete political, social, cultural, economic [and spiritual] practices. This definition recognizes the body as a site of struggle and resistance and the interwoven nature of the discursive and material in the constitution of body and experience (Moss & Dyck, 1996). It challenges prevalent notions that our experiences are primarily socially and culturally mediated and that bodies are culturally inscribed texts through which we can interpret social discourses and practices, which tends to narrow or even preclude possibilities for agency in the lives of women living with chronic illness.

The experience of living with a fluctuating (and often hidden) chronic condition also challenges the potential hegemony of the social model of disability, which assumes a fixed state of disability acted upon by social practices, thus neglecting, eradicating, denying - making invisible - the embodied experience of chronic illness. The instability and episodic nature of chronic conditions means that women who live with them "must continually renegotiate the relationship between body, self and socially constructed disability" (Meekosha, 1998, p. 175).

The negotiations I describe are not done in isolation, drawing attention to marginality and my own complicity in erasing my experience by "passing." Passing as an act of erasure requires others to see me in particular ways that make my disability invisible. In doing so, we are both complicit. To what extent do I have the power (the ability?) to influence this erasure? It depends. One of my privileges as a white, middle-class, mentally competent, liter-

ate woman is the ability to construct myself in particular ways using language familiar to other academics. Yet I cannot control how these constructions get taken up or "read" by those in the academy who have the power to influence my life and to erase or make invisible my disability. I believe that others in the academic setting have a reciprocal responsibility for making visible my disability in ways that support my interests as a woman with a disability.

After/Words...

Thus far missing from this text is how the discursive practice of traditional scholarship works "to regulate communication and to suppress the experiences and challenges of women and other Others" (McKenna, 1991, p. 117). In form (deeply abstracted) and content (erased knowledges of the history /experiences of women with disabilities), it renders our realities invisible. Kathleen Rockhill (1986) writes "...its location is in the mind, in logic, in a form of discourse which totally erases the body, the emotional, the symbolic, the multiplicities and confusions - and in all ways orders the chaos of our lived experiences so that we no longer feel their power, their immobilizing conflicts..." (p. 7).

As a women living with chronic illness and disability I am colonized by this discursivity which assumes universal and objective truths based on knowledge derived exclusively from the experience of members of the dominant group (white, Western able-bodied, heterosexual, middle-class males). Written texts represent a powerful discursive practice marking an ideological boundary of what is un/acceptable. A kind of " 'common interest' [is constructed] through which we are brought into 'reasonable' relations with each other" (McKenna, 1991, p. 125-6). These reasonable relations are especially problematic in classroom settings, where I experience others' responses to voicing my (disabled and female) subjectivity as dismissive, constituting erasure of my experience.

To speak/write my lived experiences is to transgress this boundary of 'common interest' and remain open to the possibility of constructing myself differently than that governed by ruling relations. Dominant discursive practices in the academy are encouraged, rewarded and required (Lewis & Simon, 1986) thus 'normalizing' particular realities, suppressing difference and negating my experience of disability, however complex or ambiguous. These are deeply violating (Lewis, 1993) and seductive practices requiring me to be vigilant, on the watch for erasure of my embodied self. To situate embodiment as a source of the writing that constitutes my activist practice suggests that "a powerful alternative discourse seems possible: to write [and speak] from the body is to recreate the world" (Jones, 1985, p. 87).

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